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AUTHOR Dalrymple, Nancy J.
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ABSTRACT

This self-instructional module is intended to provide basic information on autism and can be used alone or with supplementary videos. The module is divided into short sections, with each section including review questions and with a self-test (and answer key) on the whole module. After introductory material on the module's purpose and use and an overview of the module's objectives and activities, the individual sections present information on: (1) the definition of autism; (2) the diagnosis of autism including identification and assessment methodology; (3) history and theories concerning the cause of autism; (4) characteristics of the person with autism; (5) autism and the family; and (6) programs for the person with autism. Also included are a sample scenario and a module evaluation form as well as a listing of publications and videotapes available from the Indiana Resource Center for Autism. (Contains 74 references.) (DB)

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INTRODUCTION

TO AUTISM

Self Instruction Module

Institute for the Study of Developmental Disabilities

Originally Developed by:
Mary Ann Blue Gotera
Cheryl Johnson
G. Thomas Plew

Under the direction and editing of:
Nancy J. Dalrymple
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Revised August 1987
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by Nancy J. Dalrymple

INTRODUCTION TO AUTISM

1992

Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
Indiana University
2853 East 10th Street
Bloomington, IN 47405

Henry J. Schroeder, Ed.D.
Director of Institute for the Study of Developmental Disabilities

Nancy J. Dalrymple
Director of Indiana Resource Center for Autism

Layout by Allison R. Hawkins

Coordinators of Indiana Resource Center for Autism
Barbara Porco, Coordinator of Dissemination
Rozella Stewart, Coordinator of Evaluation and Documentation

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PURPOSE

This module is designed to provide an introduction to autism and to help answer the question, "What is Autism?" Every year, more is being learned about this developmental disability that will help service providers and parents be more knowledgeable. This knowledge can then be translated to better programming and better progress toward meaningful lives for people with autism. The module is self-instructional. Material from many sources was used to prepare the module.

HOW TO USE THIS MODULE

This module is divided into short sections. Each section will give you a broader understanding of the developmental disability of autism and some of the historical perspective associated with the term. As you complete the material in each section, you will find several review questions to check your comprehension of the material. Answer the questions on a separate piece of paper. Once you have completed all the sections, take the Self-Test which is located in the back of the module. Check your answers against the answer key. Mark each answer, and count the number of incorrect answers. If you missed questions, we suggest that you review the sections of the module that apply.

Audio/Visual Component

The PBS videos "Autism: Learning to Live", and "Reaching the Child Within" are recommended as supplements to this module. They will add to your understanding. Other videos might be added or substituted if they are known to be accurate and up to date. The module will stand alone without the tapes, if necessary. "Autism: Stubborn Love" and "Autism: Being Friends", made by Indiana Resource Center for Autism staff in conjunction with WTIU in Bloomington are also recommended supplements to this module. They are available for loan or sale. The video "An Introduction to Autism" is available for loan. It parallels this module.

Getting Started

Before beginning this module you may want to take out a sheet of paper and pencil to use as you complete the review questions. Turn to the next page when you are ready to begin.

OBJECTIVES AND ACTIVITIES

Institute for the Study of Developmental Disabilities
Training Module
Introduction to Autism

Objectives:

After you have completed this module you should be able to:

1. Describe the developmental disability of autism by:

a. listing the major points of the formal definition of autism.
b. stating major historical theories concerning autism.
c. identifying particular areas of difficulty for the person with autism.
d. identifying other disabilities that may occur with autism.
e. identifying the family needs and problems associated with autism.

2. Describe assessment of the person with autism by:

a. identifying the major diagnostic criteria for autism.
b. identifying assessment methodology for use with people with autism.

3. Describe intervention for the person with autism by:

a. identifying components of successful programming for people with autism.
b. identifying ways to support the individual and family with autism.
c. identifying ways parents and professionals collaborate to help the person with autism.

Activities:

1. Read the module and answer the review questions at the end of each section on a separate piece of paper. Check your answers against the key.

2. Take the Self-Test upon completion of this module on a separate piece of paper. Check your answers against the key.

3. Read over the enclosed bibliography for books which give you additional information.

4. Read the Scenario, then answer the questions on the evaluation form and turn in to your supervisor.

5. Arrange to view videotapes, if you desire.

DEFINITION

What is Autism?

One mother describes her son by saying, "He walks as if in a shadow, he lives in a world of his own where he is difficult to reach." Others describe behaviors such as lack of social response, low initiation of communication or inability to socially converse, and being upset by changes. These are only a few of the behaviors observed in people with autism. No one person displays all of the characteristic behaviors and frequency of behaviors varies. Autism is difficult to explain.

Autism is a description of symptoms that comprise a diagnosis. The condition is termed a syndrome because a group of symptoms, taken together, characterize the disorder. Autism is classified as a developmental disability. It usually is evident during infancy or early childhood. It is considered a rare disorder, occurring in varying levels of severity, in approximately one in every 1,000 members of the general population. However, it is a common disorder in a population of developmentally disabled persons, where it occurs as often as one in every five to seven persons with significant and multiple handicaps. It affects boys four times more frequently than girls, yet its toll on females is often more severe. Autism is found in individuals throughout the world, and in families of all social, economic, and racial backgrounds. Birth order has not been proven to be a factor. To date, no cure has been found. Autism is considered lifelong, yet not a progressive disability. People, with autism live a normal life span with changes in symptoms as they go through different stages of development.

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The general characteristics which define the syndrome are:

- Qualitative impairment in reciprocal social interactions.
- Qualitative impairment in verbal and nonverbal communication, and
- Restricted repertoire of activities and interests.

Because of the many diagnostic descriptions and hypotheses concerning the causes, autism has been known by many different names. Names frequently used in the past are: Kanner's syndrome, early infantile autism, early childhood autism, symbiotic psychosis, childhood psychosis and childhood schizophrenia. Pervasive Developmental Disorder (PDD) is the category under which the Autistic Disorder is found in the Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised.

Problems with the Definition

- The preceding definition is based on the 1987 Revision of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition. While much research has accompanied the formalization of the definition, it must be approached with some caution. The definition is an attempt to describe the disability so that research studies can be compared and people with autism can receive better services.

- The above characteristics will appear in different individuals in a variety of forms from mild to severe. This often causes some symptoms to over-shadow others, while at times suggesting the disappearance of the problem.

- Autism often occurs in conjunction with a range of mental retardation from mild to severe. This, as well, confuses the diagnosis of the autistic disorder. Autism may also occur in conjunction with other handicapping conditions such as cerebral palsy, deafness, or Down Syndrome.

- An accurate developmental history is sometimes difficult to obtain.

Consequently, the diagnosis of autism must be made by knowledgeable professionals working together as a team, and with family input.

HOW AUTISM IS DIAGNOSED

The cry of many parents in relation to their child with autism has been:

> *What we want and all parents need is a definitive statement from the professionals that our children have autism and not the traditional put-off of "slow development", "they'll outgrow it" or "you're worrying too much."*

Autism is often difficult to diagnose and sometimes those professionals who know it best are the most reluctant to diagnose it. They assert that those behaviors which indicate autism may result from various causes and that any two individuals with autism appear very different from one another. Consequently, the process of obtaining the diagnosis of autism is often a merry-go-around of visits between doctors, therapists, psychologists and other service providers before the definitive diagnosis is made.

Diagnostic Criteria

The most common and current criteria used today to diagnose autism is the DSM-III-R (published by the American Psychiatric Association). The following chart details the major points of diagnostic criteria used over the years.

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COMPARISONS OF DEFINITIONS OF AUTISM

Autism Society of America, Inc. - 1978

- Onset before 30 months
- Disturbance of response to sensory stimuli
- Disturbance of speech, language, cognition, and nonverbal communication
- Disturbance of capacity to relate appropriately to people, events and objects
- Disturbance of developmental rates and sequences

Diagnostic and Statistical Manual III - 1980

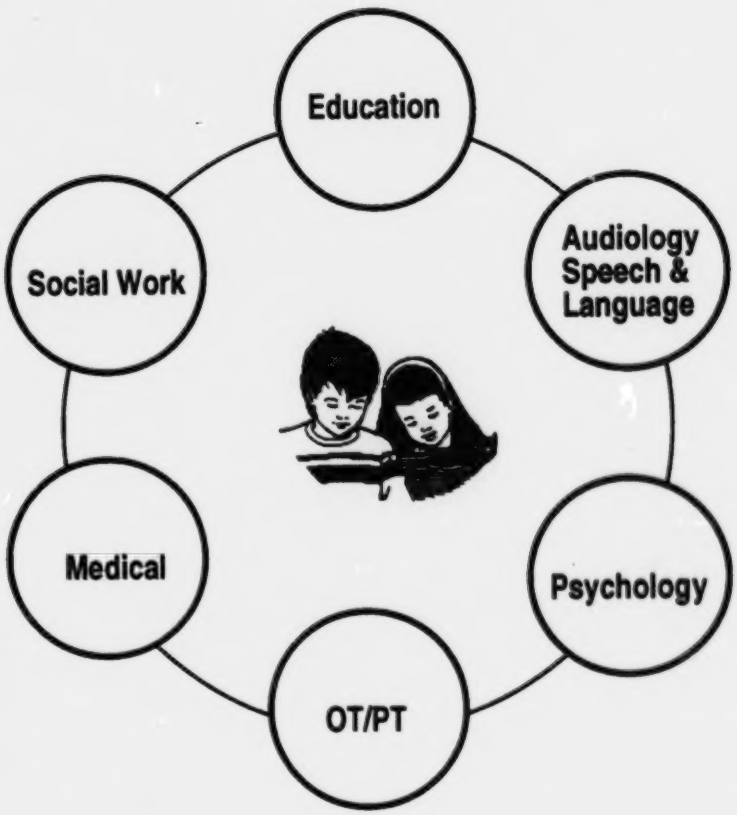
- Onset before 30 months
- Pervasive lack of responsiveness to people
- Gross deficit in language development
- Peculiar speech patterns
- Bizarre responses to various aspects of the environment
- Infantile Autism Residual State: Once met the criteria, currently shows signs of oddities of communication and social awkwardness

Diagnostic and Statistical Manual III-R-1987

- Onset during infancy or childhood
- Qualitative impairment in reciprocal social interaction
- Qualitative impairment in verbal and nonverbal communication and in imaginative activity
- Markedly restricted repertoire of activities and interests

IDENTIFICATION AND ASSESSMENT METHODOLOGY

Since the diagnosis of autism brings lifelong change to the family situation, it is the desire of professionals to develop a plan for the identification of individuals with autism that results in the lowest number of misdiagnoses while fully considering the needs of the individual. The plan that has proven to be the most useful in recent years is one that combines diagnosis with assessment and is based on an interdisciplinary approach. This method utilizes several disciplines to assess the individual's level of functioning, learning style, and developmental history; then a diagnosis is formulated based on the information. The figure below diagrams the interdependent parts of this method which will then be briefly discussed. It is easiest and most beneficial to make a diagnosis early in a child's life, when the maximum benefit can come from intervention strategies.



Education

Due to the fact that autism affects the person and the method by which he learns, the educational professional adds a special dimension to the assessment. The future of people with autism will greatly depend on the teaching they receive. Teaching must deal with the most effective ways the person learns in the least restrictive manner. The educational professional's input into the selection of the program and special interventions and adaptations that can specifically help the learner is essential.

Audiology, Speech and Language

Individuals who may have autism are often evaluated by an audiologist either as part of the multidisciplinary assessment or as a referral from a pediatrician. This referral is often suggested to rule out conditions such as hearing loss as a possible cause of unresponsive behavior. The role of the speech pathologist in the diagnosis and treatment of autism is a primary one. The speech pathologist will be interested in evaluating not only speech disorders but the total communication ability of the individual including the social use of language in daily living. Particularly, the speech pathologist will evaluate:

* the communicative intent of behaviors,
* expressive communication,
* effectiveness of various communication strategies, and
* receptive communication.

Consequently, the speech pathologist is primary in evaluating and suggesting therapies for communication and communication strategies for persons with autism.

Parent or Other Family Member

The family must be represented on the team. They know the person best and are the only ones with the historic and longitudinal perspective. They also know the person in numerous settings and across time spans. They also are invested in a way no professional can be.

Social Work

A social worker is often involved in the assessment of individuals with autism in order to provide the family with information about the dynamics that may be present with the disability. The social worker may also be responsible for gathering information about current adaptive functioning and early developmental history. As such, the professional will often give special attention to the patterns of interaction among the family members as well as the family members' perceptions of the individual with autism. Since autism is a family as well as individual problem, the social worker can aid in the development of routines and family guidelines for positive interaction. The social worker can also support the family and help them find appropriate services.

Medical

The medical doctor, while often the first avenue in determining the problem with the individual, should not be overlooked in the actual diagnosis and treatment of autism. In fact, the medical profession offers a wealth of information which can aid in the diagnosis, namely:

- review of previous medical records,
- family medical history,
- physical exams and specific diagnostic tests, and possibly
- comparisons to normal development

Psychology

A psychological evaluation yields important information about cognitive functioning. It is a comparison of the level at which a given person would be expected to be functioning, given his or her cognitive skills, and the level at which he or she is currently functioning in the areas of communication and social interaction, that particularly helps professionals determine a diagnosis of autism.

Occupational Therapy/Physical Therapy (OT/PT)

The involvement of the OT/PT in diagnosis may give the family a more complete understanding of the areas in which the individual may be developing at an average rate as well as those where remediation therapy is necessary. This is especially important to the person who may also have perceptual problems which often accompany autism.

With all this information in hand, the interdisciplinary team can develop a plan which will attend to the social, cognitive, communicative, and sensory needs of the person with autism. Thus, it can be readily seen that the use of an interdisciplinary approach best guarantees that the needs of the person and family with autism be met in terms of an appropriate diagnosis and treatment strategy. The combination of the expertise of this group of professionals can provide hope and encouragement during a period of time when the family is extremely dependent on such expertise and support. One must remember, however, that the goal of this group is an intervention strategy which will allow the family and individual to live to their fullest potential. The next section of this module describes some successful intervention strategies.

REVIEW QUESTIONS 1

1. Check **all** of the following criteria that are used to diagnose autism:

   - ☐ Impairment in ability to communicate
   - ☐ Impairment in reciprocal social interaction
   - ☐ Bizarre noises and movements
   - ☐ Gross deficit in language development
   - ☐ Self-injury and aggression
   - ☐ Disturbance of rate or sequence of development
   - ☐ Markedly restricted repertoire of activities and interests

2. List six disciplines that might be used in an interdisciplinary assessment of a person with autism.

3. Which of the following are not true?

   a. Autism is described through observing behaviors.

   b. Autism is a syndrome.

   c. Autism is common in males.

   d. Autism is a developmental disability.

   e. Individuals outgrow autism.

4. Which one of the following is true?

   a. Autism occurs 4 times more frequently in girls than boys.

   b. Prevalence is about 1 in 1,000 in the general population.

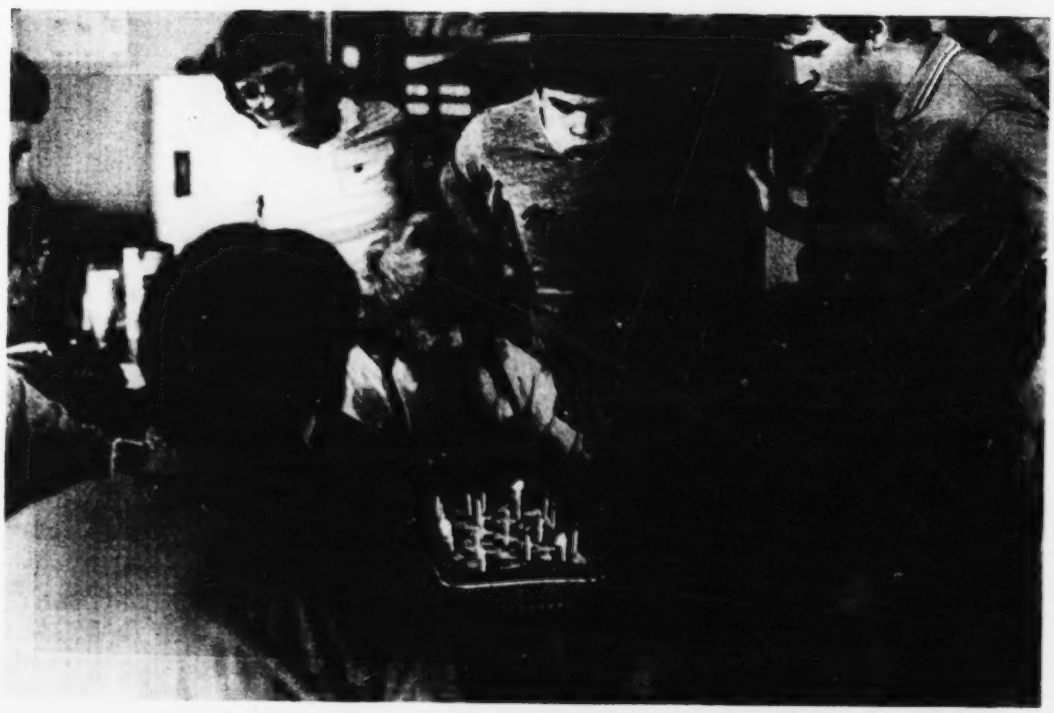
   c. Youngest children in the family are most often affected.

   d. Autism rarely occurs with mental retardation.

   e. Autism occurs more in the higher socioeconomic levels.

HISTORY AND THEORIES CONCERNING CAUSE OF AUTISM

Cases of autism have been documented since the French physician, Itard, brought forth a description of a 12 year old boy found living in the forest during the French Revolution. In 1943, Leo Kanner introduced the term, early infantile autism in his famous journal article in which he described 11 children who had a common and "extreme aloneness from the beginning of life and an anxiously obsessive desire for the preservation of sameness." Kanner's article triggered a major controversy between the proponents of autism as an emotional versus organic disorder. The war that erupted continued into the early 1980's. A broad overview of both of these schools will be presented. However, it should be noted that current research strongly supports current theories that autism stems from a central nervous system disorder and **not** from emotional problems.



Emotional Disturbance Theories

The emotional disturbance theories consider the cause of autism to be one of "nurture". Their aim is to trace the cause of autistic behavior to an event or chain of events in the early life of the child that abruptly halts normal development. As such, the development of autistic behavior is directly linked to something enacted or not provided by the parents of the individual. Bruno Bettelheim, Frances Tustin, Bender, and Mahler have written from this perspective.

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Bruno Bettelheim's theory was first published in 1967 in a work titled The Empty Fortress. In this publication, he described how subtle parental attitudes toward their child resulted in autism. He concluded that in all cases of autism known to him, the prevailing parental attitude which the child experienced was a "wish that he did not exist."

Laurette Bender in 1947 described how autism represented a form of schizophrenia and Margaret Mahler in 1952 wrote that autism was a "symbiotic infantile psychosis" where there was a pathological dependence between the child and the parent, usually the mother. Tinbergen in 1974 said that "autistic children are potentially normal children whose affiliative and subsequent socialization processes have gone wrong in one way or another, the problem being traceable to something in the environment."

Tustin's work on autistic behavior began in her book titled Autism and Childhood Psychosis published in 1973. Here she described two situations which she believed would result in autism. The first situation was termed "abnormal primary autism" and was used to describe the failure of the child to develop from the normal primary autistic state to a state of independence. The second form of autism described by Tustin was termed "encapsulated" where the infant experienced separation from the mother too early. She explained that an experience of traumatization occurs and the child consequently shuts out the world and creates a virtually insurmountable barrier.

The impact of the above theories that autism is the result of an emotional disturbance were profound. More specifically:

- parents experienced guilt and defensiveness
- services to children were either inappropriate (i.e., play therapy, parental therapy) or delayed
- an impasse developed between parents and professionals, and
- parents resisted the diagnosis

Biogenic or Developmental Disability Theories

Springing from the inconclusive evidence derived from research of the 1970's a biogenic based theory concerning the origin of autism developed. This school of thought considers the cause of autism to be "nature." These early theories were further promoted by the following known facts concerning autism:

- presence early in life suggested a biological problem
- linkage to conditions which produce central nervous system impairment suggested a biological correlation, and higher incidence of autism among mothers contracting rubella during pregnancy suggested a biologically based condition

As research continued along these lines, it has become evident that a single cause for the disorder will not be identified; rather, a number of different conditions can result in autism. Three such causes which have been identified to date are:

- genetic - a chromosomal abnormality
- biochemical - a chemical or metabolic abnormality, and
- viral - a prenatal viral infection resulting in central nervous system abnormality

Interactional Theories

Theories concerning the nature of the disability which results in autism took three variant directions under:

- Ornitz and Ritvo
- Hermelin, and
- DeMeyer

Since each of these theories are considered viable, they will be reviewed briefly.

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Ornitz and Ritvo developed a theory termed "perceptual inconsistency" in a publication in 1968. Here they suggested that the onset of autism was created by a disturbance of modulation of perception. This disturbance creates unusual perception of some sensory receptors over others. As this preference develops, it becomes so intense it blocks out others receptors.

Hermelin developed a theory focused on impairment in abstract memory in 1968. This theory was termed "central cognitive defect" and suggests that individuals with autism receive sensory input but cannot extract information from such. She suggested that passive imprinting is possible, but the person can neither plan nor take active steps to aid the memory process.

A third biogenic theory was developed by DeMyer at the Indiana University Medical Center in Indianapolis in 1971. Her theory was labeled the "cross-modal association defect." In this theory she suggests that autism is caused by defects in transferring information from one learning mode or sensory mode to another. She notes that children are normally adept at receiving information through one sense and responding in another.

However, she observed that individuals with autism not only have difficulty in receiving an auditory cue and responding verbally, but they show problems in transferring information from visual to motor, auditory to fine motor and other such transfers. It was further noted that individuals with autism appear to experience problems in being overselective or unable to generalize from one modality to another.

In summary, although no one cause for autism has been found, much progress has been made. Most researchers today view autism as a developmental impairment of biogenetic origin in the central nervous system. However, this is not to say that all the strongholds of early emotional disturbance theory have been destroyed. In fact, such individuals as Dr. Leo Tinbergen and some experts in other countries still strongly support such a thesis. This situation as well as low occurrence of the condition has promoted the following assessment of our current situation regarding autism:

* a misunderstanding by the general public as to the nature of autism exits
* this general misunderstanding has resulted in a lack of clear direction on a national or state level for intervention strategies for individuals with autism
* there exists a general hesitation of the medical and psychoeducational professions to give a much needed early diagnosis, and
* there is a general lack of understanding of the broad potential for the individual with autism, perhaps due to their impairment in social interaction skills

As a result of the work of a number of well qualified professionals, the field of autism and intervention strategies is experiencing progress. Some of the individuals involved in this effort are listed below with their particular fields of interest.

• Behavior	– Favell, LaVigna, Donnellan
• Communication	– Carr, Prizant, Schuler, Wetherby
• Family Needs	– Kozloff, Bristol, Powell, Powers
• Programming/Interventions	– Schopler, Rutter, Wing, Mesibov, Koegel, Rimland, Leventhal
• Integration	– Lovass, Strain, Odom
• Etiology	– Ritvo, Coleman, Cohen, Courchesne, Bauman, Gillberg
• Diagnosis/Outcome	– Tsai, Lord

Current Medical Research:

Courchesne's studies indicate that people with autism have greater difficulty in all areas of attention. There are problems with shifting attention, affecting engagement and disengagement.

Current Epidemiology Studies:

By studying entire populations and tracing family histories, Ritvo has located families with several children with autism. There are also family histories that reveal autism or related disorders of communication across generations and relatives. Ritvo predicts from his studies that the chances of having a child with autism increase if there is one child with autism in the family.

REVIEW QUESTIONS II

1 Which of the following is the current and most prevalent thought concerning the etiology of autism?

   a. a combination of genetic and biogenic factors.

   b. a combination of emotional problems

   c. a combination of environmental factors

2. Who first described autism?

   a. Bettelheim

   b. DeMeyer

   c. Ritvo

   d. Kanner

   e. Tinbergen

3. Check the following phrases that go with the theory of autism being an emotional disturbance:

   a. Refrigerator mothers

   b. Perceptual inconsistency

   c. Central cognitive defect

   d. Wish not to exist

   e. Cross-modal association defect

   f. Separation from mother too early

4. Which of the following are reasons for a lack of understanding about autism?

   a. Parents don't care or understand

   b. Confusion about diagnosis

   c. Reluctance of professionals to diagnose emotionally disturbed patients

   d. The cause of autism in not known

   e. Uninformed professionals who don't understand the reasons diagnosis often helps the person to receive better programming

   f. The heterogeneity of the disorder

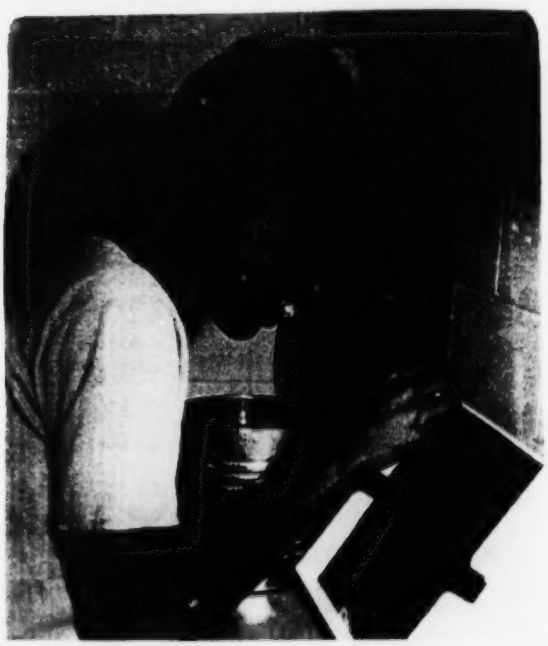
CHARACTERISTICS OF THE PERSON WITH AUTISM

Since autism is a description of a condition defined by certain characteristics, it is important for health care and service providers to be cognizant of these characteristics. While they may appear in any number of combinations, the presence of many of these together is reason to begin a full assessment of the actual condition.

For discussion purposes the characteristics associated with autism have been divided into four major categories. Specifically, these are:

* social characteristics,
* communication characteristics,
* unusual behavioral characteristics, and
* learning characteristics.

These characteristics have not only been developed to classify the disorder , but to indicate the specific areas of difficulty associated with autism.



A listing of personal strengths and preferences is helpful to include in order to emphasize the positive characteristics of persons with autism and to give information on areas to emphasize and build upon. Teaching to deficits only leads to frustration and failure. The following pages will detail each of these characteristics in a chart format for reference and learning purposes.

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Social Behavior Characteristics

Since the early days of describing the syndrome of autism, the problems in the area of social behavior have been mentioned. Impairment in social interaction behaviors are apparent in some degree of severity in all individuals with autism and will often make up a major portion of the individualized, positive program.

Behavior in Normally Developing People	Behavior Associated with Individuals with Autism
Almost inherently seek relationships with people	Relate to people with difficulty
Generally trust people	May fear new people or places
Develop awareness of social cues	Lack understanding of social cues
Use eye contact frequently	Avoid or use eye contact in odd ways
Desire company	Need to be alone frequently
Develop stronger attachment to people than objects	Develop strong, sometimes inappropriate attachment to objects
Respond appropriately to situations	Giggle, laugh, scream inappropriately
Play imaginatively	Lack imaginative play early in life
Play appropriately with toys	Often use toys in odd ways - lining up,spinning, etc.
Empathize with others	Lack understanding of how others feel
Express emotions appropriately	Often express emotions inappropriately and have a narrow range
Develop growing understanding of social/sexual norms	Lack social/sexual understanding
Increasingly are able to share and cooperate with others.	Must be specifically taught to share, cooperate, and be aware of others.

Communication Characteristics

The communication abilities of persons with autism comprise some of their major difficulties. Expressive and receptive language skills are only two of the windows into the individual's world, but two extremely important ones. While most individuals develop normally in the area of verbal and nonverbal communication, individuals with autism have great difficulty with interactive communication. It should be noted that these behaviors are not ones of choice, but inability. Often the parent or professional confronted with a noncommunicative individual feels that s/he could respond if s/he only desired. In autism, this is not true! Impairment with the ability to communicate is a major indicator of autism. Differences among people with autism vary, from about 50% being nonverbal to some higher functioning people being extremely verbal, but all having difficulty with communicative interactions.

Behavior in Normally Developing People	Behavior Associated with Individuals with Autism
Use gestures and respond to gestures	Slow in using and understanding gestures
Produce sounds early with normal speech development	Speak infrequently or not at all (50% of persons with autism)
Gain appropriate concepts easily	Have difficulty understanding abstract concepts
Answer questions appropriately	Have problems answering even simple questions
Understand content of communication	Lack comprehension of content and timing of communication
Can talk at length on one or more topics	Perseverate on one topic, may ramble
Follow a line of several exchanges	Follow a line of exchanges with difficulty
Use communication for social exchanges	Have difficulty communicating socially
Initiate communication	Initiate communication infrequently or repetitively
Express feelings through words	May use behavior to express feelings

Unusual Behavioral Characteristics

Individuals with autism often explore the world in unusual ways using their senses of touch, taste, and smell. They may also use vision and hearing in odd ways. In general, one can notice that individuals with autism are experiencing sensory difficulties by their inappropriate response to surrounding stimuli. This response ranges from super sensitivity to some stimuli to lack of or very delayed response to others. This may occur between individuals or within the same person.

Behavior in Normally Developing People	Behavior Associated with Individuals with Autism
Actively respond to the full range of sound stimuli	Act deaf and/or very sensitive to some sounds
Enjoy diversity	Resist change in routine, people, environment
Demonstrate appropriate fears	Lack fear of real danger
Exhibit socially appropriate movements	Exhibit repetitive body movements such as rocking, pacing, hand flapping
Explore environment widely	May stare or fixate on objects such as lights, mirrors, or fans.
Explore environment through integrated sensory experiences in an appropriate manner	Explore environment by inappropriate methods such as licking, smelling, handling
Exhibit attention span appropriate to activity	Perseverate or have short attention to activities
Look directly at people and objects	Use peripheral vision rather than straight on and/or avoid looking
Enjoy physical contact	May avoid human contact in favor of objects or visual stimuli

Learning Characteristics

Given many of the other characteristics and areas of difficulty, it becomes apparent that the individual with autism will experience problems in the areas of learning. These problems can be further complicated when one considers that 60% of individuals with autism have an IQ under 50 and only 20% have an IQ above 70. These higher achievers represent the whole range of normal intelligence. Thus, learning characteristics of some people with autism may parallel those of individuals who have been diagnosed as mentally retarded, but are compounded by the additional disability of autism. Higher functioning individuals may have similar characteristics to people with learning disabilities.

Behavior in People who are Developing Normally	Behavior Associated with Individuals with Autism
Develop fairly evenly within and across skill areas	Develop unevenly within and across skill areas
Enjoy change in learning environment and tasks	Resist change in learning environment; perseverate
Can fill unstructured time with constructive activity	Have difficulty with unstructured time and waiting
Generalize skills to other areas	May not generalize skills to other areas and places
Understand abstract concepts	Have difficulty with abstract concepts
Usually are predictable and consistent	Often exhibit impulsivity and inconsistency
Process many stimuli at once and can integrate them into a whole	Overselective to one or more stimuli with failure to understand the whole
Organize, plan, and make choices	Need to be taught how to make choices, decisions, and plans
Strive to become independent	Rely on cues, learned routines, and familiar people
Enjoy competition	Usually not competitive
Learn early by imitation	Often must be taught to imitate and what to imitate
Can shift attention rapidly and focus and remain attentive	Have problems with attention shifts and focus.
Develop problem solving skills	Must be taught problem solving strategies that are situation specific.

Characteristic Strengths

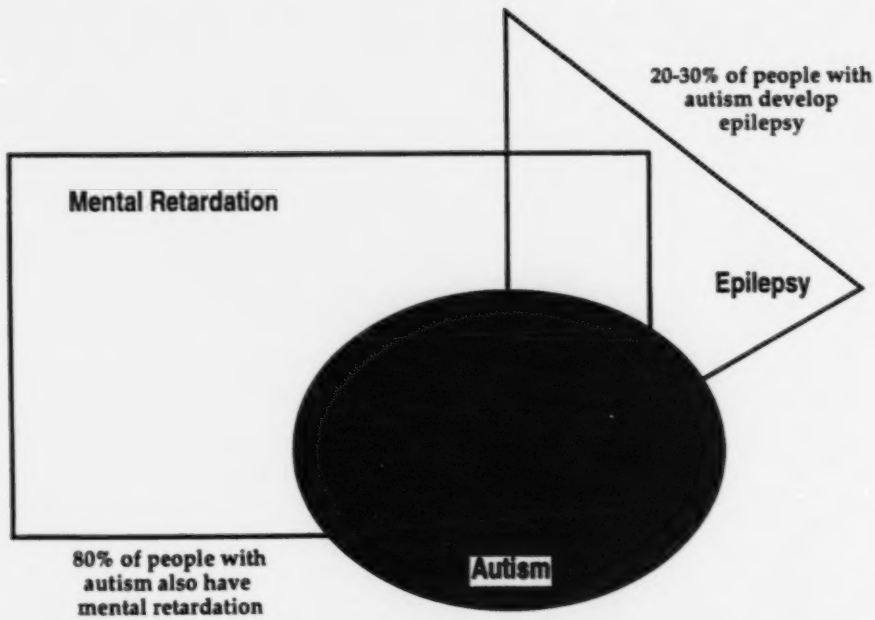
While the developmental disability of autism is often described by inappropriate behaviors in several areas, an overview of the disorder would not be complete without describing some of the characteristic strengths that are more commonly possessed by some individuals with autism. While some of the learning characteristics of the person with autism may seem undesirable, some of these may actually contribute to strengths. Typically, the strengths that have been commonly noted in some people with autism are:

- Stamina - probably directly related to the general characteristic of repetitive behaviors, this condition actually contributes to the ability of the person with autism to stick to a task until it is completed, even though it may be arduous.
- Well developed gross and fine motor skills - while the motor skills of the person with autism may develop more slowly, some of these skills, once attained, may become a strength . This should not be surprising since the acquisition of motor skills is a direct result of repetitive behavior which practices that skill. An individual may have a strength in one area of motor development such as manipulating objects, but have poor paper/pencil skills. Therefore it becomes important to assess carefully within skill areas.
- Enjoyment of routines - although the desire and almost demand for a set routine in childhood may have been seen as an inconvenience and problem, the individual with autism often can utilize this very characteristic as a strength in personal and vocational management as long as interfering compulsions are kept in check.
- Good long term memory - it should be noted that it is the assimilation and organization of information that presents difficulty for persons with autism. Once this information has been recorded in a manner that promotes recall, long term memory may be equivalent to other individuals and sometimes better in some areas, such as for numbers, dates, names, or routes.
- Accuracy - the person with autism is usually recognized as performing tasks accurately once they are learned. The need for sameness in persons with autism often results in a high level of accuracy in the completion of familiar tasks and routines.

For some, these strengths may be viewed as general outcomes of the disability, but should also be seen as avenues to be utilized to promote the vocational, educational, recreational, and self management skills.

Other Developmental Disabilities and Autism

One of the difficulties in diagnosing autism and studying the effects in the general population has been its co-existence with other developmental disabilities which have often overshadowed the recognition of autism. This has been especially true when the other disability is extremely severe and the behavior which would have suggested autism is attributed to another disability. The following figure diagrams the interplay of other disabilities and autism.


20-30% of people with autism develop epilepsy
Mental Retardation
Epilepsy
80% of people with autism also have mental retardation
Autism

In summary, 80% of the individuals with autism have an IQ below 70 and at least 20% of them experience epileptic seizures. These facts should have an impact on the need for a total evaluation and intervention strategies for persons with autism to guarantee that all the problems are addressed. People with autism also may have cerebral palsy, Down syndrome, or be blind or deaf. These additional disabilities are not commonly paired with autism, but combinations do occur. Just recently, Rett syndrome has been identified in females. The characteristics of this syndrome look much like autism in the early years. Other problems such as thyroid deficiency, PKU, Fragile X, and Tourette Syndrome sometimes occur in people with autism. These known facts add to some of the confusion surrounding the diagnosis of autism.

REVIEW QUESTIONS III

Of the characteristics listed below, mark those often associated with autism with an "A":

- ☐ 1. Perseveration
- ☐ 2. Love of diversity
- ☐ 3. Poor or odd eye contact
- ☐ 4. Imaginative play
- ☐ 5. Answers questions appropriately
- ☐ 6. Lacks fear of real danger
- ☐ 7. Repetitive movements
- ☐ 8. Staring at objects
- ☐ 9. Problems with abstract concepts
- ☐ 10. Initiation of communication
- ☐ 11. Mental retardation
- ☐ 12. Strong attachment to objects
- ☐ 13. Explores environment through odd use of senses
- ☐ 14. Generalizes learning to other situations
- ☐ 15. Strives to be independent
- ☐ 16. Overselective
- ☐ 17. Good long term memory
- ☐ 18. Cerebral Palsy and Down Syndrome

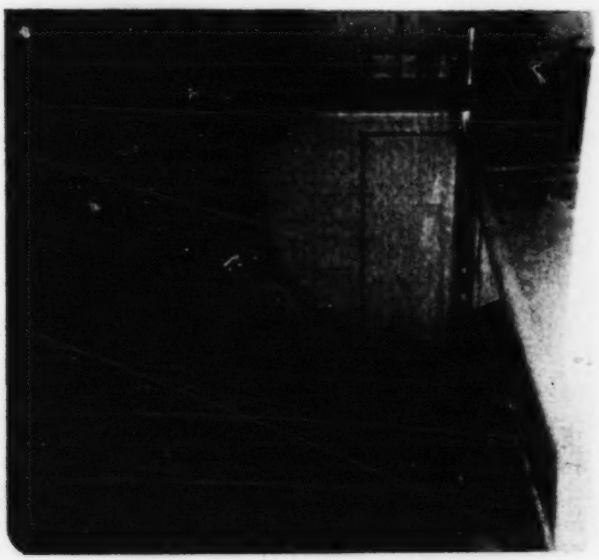
AUTISM AND THE FAMILY

Autism is more than a problem which affects a person, it is a developmental disability which affects the entire family. Parents describe living with an individual with autism in many ways: painful, time-consuming, disruptive, humorous, traumatic, but sometimes deeply rewarding. Adjusting to life with autism is similar to adjusting to life with other lifelong disabilities, but the recognition of this lifelong commitment sometimes eludes the family that is beginning to deal with the news.

Life with a child with autism can be an around-the-clock job. It means loss of sleep for parents of individuals who sleep intermittently. It may mean dealing with unpredictable tantrums. It may mean feeding, dressing, and changing a person as if he were an infant until he is taught to take care of his own needs. It means patience and persistence in breaking simple operations down into steps and teaching them in a systematic way.

The commitments of time and energy demanded by an individual with autism understandably impose severe strain on a family. Hopefully, the extended family and friends can help. Brothers and sisters may have trouble at first understanding why their parents are providing one child with so much attention. They may not like to bring their friends home because of their sibling, or they may be angry with him for breaking or damaging their toys. There is a positive side to this, however. It is helpful for children to learn that the needs of other people can be more urgent that their own and that they can help their brother or sister grow to his/her greatest potential. Families are often creative and adaptive in unexpected ways when they come together to meet the needs of a member with autism.

The focus of this section of the module is to recognize the long term implications of autism and to address some coping strategies for them.



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Emotional Impact of Autism

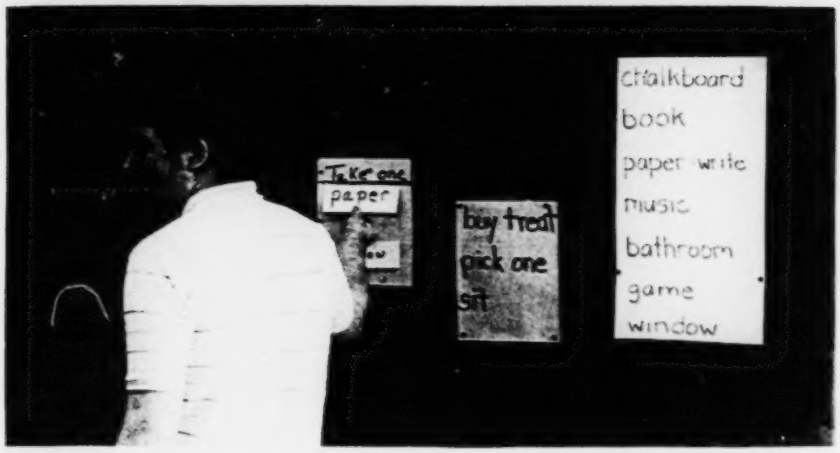
Perhaps one of the most difficult aspects of dealing with autism is the emotional impact that it may have on the family. While one individual suffers the problems of the disability, all the family members, especially the parents, suffer the emotional strain. The anticipated joys that had surrounded the arrival of this new individual in the home may soon be overshadowed by the strain of the person's "difference." Recognition of the expected emotional reactions to autism is perhaps one of the greatest aids to overcoming them. When parents and siblings know that what they feel is to be expected and is a normal reaction to their situation, they can then locate therapeutic methods of overcoming the fears and concerns.

As with the condition itself, emotional reaction to autism spans the life of the family. The following chart details the stages of life and some of the family reactions from parents and siblings.

Family Reaction to Autism

Life Stage	Common Reactions
When Diagnosed	Depression Guilt Anger Feelings of deep conflict Struggles for solution
During School Ages	Isolation Need for family support Sibling rivalry Advocating for service
Adolescence	Conspicuous Feeling of entrapment Momentary loss of hope Fear about the future Need to plan for adult years
Adult years	Desire to protect person - lifelong Desire to plan for life without children Struggle to find services

While these family emotions can be threatening, being aware of them may prompt families to seek help early, thereby helping the family unit to grow and mature, permitting individuals to reach their full potential.



Surviving the Impact

Parents have found, through a diverse number of channels, that family survival in spite of a member having autism is possible, although difficult. While supporting the needs of the individual with autism, the family has learned that there are certain strategies that it can use to better bear the impact that autism plays emotionally, physically, and intellectually on that family. Some of the strategies that are recommended include:

- Do not hide the individual. The more the general public and friends know about the person with autism, the more understanding and supportive they can be; however, they may need to be educated. This means that the family must shield itself from unsolicited comments and advice.
- Utilize outside help to allow time together for recreation and fulfillment of family needs. Push the service delivery systems for trained respite care.
- Contact a parent group that understands autism. A local support group or Autism Society of America chapter can be very supportive and informative.
- Become informed. Contact a state or regional Resource Center, go to your library, contact the Autism Society of America.
- Maintain a sense of humor, no matter the outlook. Enjoy the sense of joy and humor that this individual is bringing to the family's life. This will require some help at times.
- Work together as a family to provide needed respite time for each other. Expect help from others and express what you need clearly.
- Arrange daily schedules for attention to the needs of the whole family. Help the person with autism learn to understand that there are needs of others that sometimes take precedence.

* Develop a structured routine for the individual's care. Remember that this does not mean protecting the person from the world. People with autism have to learn to be flexible, and cope with life to the best of their ability, but the teaching needs to be systematic over time.

* Develop a network of support. Professionals should avoid blaming or criticizing the family for the way the individual is being handled and family members should openly discuss needs with professionals.

* Protect your own health, since poor health and exhaustion affect the ability to cope. Try to eat properly, get rest and exercise and find time for recreation away from the demands of the home. This is much easier said than done. However, each family member is important.

* It's hard to remember that there are no clear-cut answers. Sometimes the harder you try, the worse things will seem. Like many other chronic problems, there are joys and sorrows; gains, plateaus, and failures. Keeping a long term perspective and enjoying the small victories will help.

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PROGRAMS FOR THE PERSON WITH AUTISM

Programs to educate people with autism will not cure or make them non-handicapped. However, even though people with autism may have severe learning problems, they can learn social behaviors and become contributing adults. A few may be able to live independently. Many can work with support. No single educational model will be suitable for all persons with autism; therefore, a range of educational services is needed -- from specialized, individual programs to placement in a generic program with support services only.

Finding the educational program suitable for the student with autism is not typically the problem it once was. The Individuals with Disabilities Education Act of 1990 (P.L. 101-476) entitles persons to a free and appropriate education with the burden being placed on the state. The bill provides for incentive grants to state and local education agencies to educate persons who are handicapped. However, many adults with autism are excluded from services since there are no mandatory laws requiring agencies to provide programs. Preschool programs for the 3-5 year olds with disabilities are now mandatory for the public schools. The development of interactive social and communication skills and the opportunity to be in programs with sociable peers should be emphasized. Early intervention is strongly advised.

Programs must be individually tailored for students in the public schools for their education to be "appropriate " and in the "least restrictive" environment possible. Appropriate and least restrictive education is assured by the requirement that each student receives an individualized education plan(IEP). School systems are required to provide a number of alternative programs to fit the needs of their students, and must provide each student with the opportunity to experience as normal an educational setting a possible. The IEP sets forth the short and long term goals for the student, the services which the student will receive, and the degree to which the student will participate in the regular programs offered by the school. Functional, age- appropriate skills and behaviors should be emphasized with the addition of vocational work experiences in the programs of secondary students' programs. Learning social interaction skills and communication skills must receive priority across all ages of people with autism.

One key to successful educational programs for persons with autism is innovative, creative, and positive teachers who are specially trained to work with persons with autism, and are willing to work closely with parents, therapists, psychologist, counselors, social workers, other educational and support staff, and community people. A structured, consistent program with continued assessments and adjustments is necessary. Students also must learn to function in natural, community settings; therefore, the classroom must expand beyond the school walls.

Building a Positive Program to Teach Appropriate Behaviors

A student with autism can benefit from a program in which s/he comes in contact with a variety of other students and adults. Educating students with autism requires the use of positive behavior support planning.

It is necessary to analyze the purpose or function of the behavior in order to successfully replace the undesirable behavior with new skills and behaviors. The new behavior must be just as efficient at fulfilling the original purpose. For example, if pinching gets the student out of an uncomfortable situation, teaching him to gesture "go away" might be a successful strategy. The following is a format for analyzing behavior management techniques.

Stimulus/ Antecedent Environment	Behavior to Change	Purpose of Behavior	New Behaviors/ Skills to Teach	Instructional Environmental Plan	Reinforcement Plan

An environment should be created that develops and fosters behaviors that will contribute to the individual's ability to live as independent and productive a life as possible. A positive, consistent, structured program emphasizing functional skills, including communication and social skills, often in itself reduces behavior problems. Techniques are available for trained and adequately staffed programs to provide the positive programming necessary to reduce most interfering behaviors.

Questions to Answer in Planning a Positive, Individual Program Plan:

* What are the targeted behaviors and what are their function(s) for the person?
* How does someone communicate with the person effectively?
* How does the person with autism communicate?
* What frustrates, distracts, upsets the student?
* What is the best learning environment for the student?
* How does someone redirect this student?
* What motivates the student?
* What are strengths and weaknesses of the student?
* What are appropriate teaching strategies based on the student's needs?
* What are the likes and preferences of the student?

* What sensory issues does the person have?
* What social skills does the person have or need to learn?
* How does the person learn best?

All people with autism need to have an individualized program. Understanding how the impairments in social interaction skills, communication skills, and sensory needs interface with the learning needs of the person is vital to designing a comprehensive program plan. This plan needs constant evaluation and will evolve as the person grows and learns. However, a longitudinal approach is needed to help the person mature, become independent and responsible, and be a productive member of the community.

Strategies that help a person with autism learn

For the person:

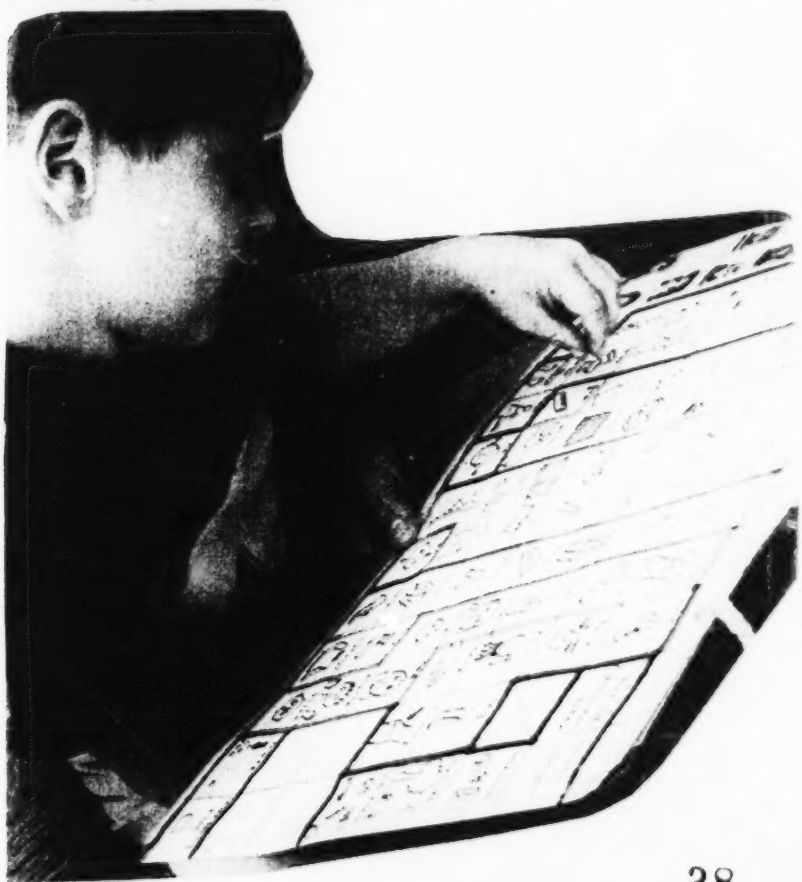
* Be with sociable and supportive peers and adults
* Watch others do activities
* Experience doing activities the same way
* Have available a picture/written sequence of the day, week, and activities
* Do activities simultaneously with others
* Partially participate, when needed, to assure success
* Have a concrete definition of amount to do - what does "finish" mean?
* Have a concrete definition of quality
* Be able to request and refuse appropriately
* Be reinforced by others or from the activity

For those teaching people with autism:

* Use positive approaches rather than corrective means
* Communicate with words, gestures, pictures, objects, and demonstrations at a pace that the person understands
* Control competing stimuli when needed
* Account for time needed to shift attention and process information
* Use preferred activities that use strengths
* Provide ample opportunity for choice making
* Teach useful, meaningful activities

- Plan for independence and generalization
- Teach in the context where the skill will be used
- Plan learning sequences carefully
- Provide concrete, clear information about time frames, amounts, changes, and expectations
- Provide the needed prompts and supports to assure learning

Because people with autism do not understand or portray social cues and nuances, they are often viewed as difficult to teach. They can learn in a group situation if they are helped to know what stimuli should receive their attention. They can be helped by peers, if the peers understand how to help and are supported to do so. They can learn to be productive and accurate workers, if their unique needs are met. Too often directives that tell people what not to do are the most prevalent teaching techniques, rather than concentrating on teaching the appropriate behaviors and skills. Competition, social pressure, and negative consequences usually make the person with autism more anxious. Therefore, concentration on an overall positive, success oriented program that enables the person to learn through doing meaningful activities will usually be the most useful. Cooperative learning, facilitated communication, community based instruction, and supported work, living, and recreation all allow for a positive, supportive approach.



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REVIEW QUESTIONS IV

1. Which of the following are typical family emotional reactions to receiving the diagnosis of autism?

   a. isolation
   b. guilt
   c. loss of hope
   d. anger
   e. depression

2. List three ways a family might survive the impact of autism.

3. Which age groups are entitled to programs by federal law?

   a. preschoolers
   b. school age students
   c. adults
   d. aging adults

4. Why should students with autism be taught with other students?

5. Is the function of a behavior important to know? Why or why not?

6. Can behavior be modified in natural settings?

7. What skills and behaviors must receive priority and be emphasized?

8. List six general strategies to remember when teaching someone with autism

SUMMARY

Today, as opposed to a few years ago, autism is recognized by state and local laws as a separate handicapping condition. No longer can people with autism be excluded because of their disability. However, as the recognition and understanding of autism has grown, so has the frustration with available services and lack of trained professionals. This population has generally been under and poorly served.

As integration, inclusion, and supported living, working, and recreating become realities for many people with developmental disabilities the need for experienced, knowledgeable teachers for people with autism escalates.

Teaching must be individualized and systematically applied across time, peers must be involved, and interactive communication emphasized. People with autism could be left out of the current changes and moved back to isolation, if their unique learning needs are not understood and accommodated. Their social, sensory, and communicative impairments often make typical group teaching inappropriate. Adults, who have spent years in isolated institutions will require equal time and careful teaching so they can learn natural community skills and behaviors.

However, these unique individuals are a resource we no longer can afford to neglect. They offer society special ways of looking at the world. There is room for people who are "unique" and "different". There is wisdom in teaching and knowing the individual, rather than applying rigid rules and standard curriculum to everyone.

To know a person with autism, one has to be an interpreter, detective, and statistician. One must slow down, view the world through that person's eyes, and adapt. One also must loosen strict social scripts and refuse to be "embarrassed" or to set up power struggles.

People with autism need support to succeed. And they very much desire success and acceptance. Understanding more about the disability of autism is only the beginning of understanding and effectively helping people with autism.

APPENDIX

Self Test
Answer Keys
Bibliography
Scenario
Evaluation Form

SELF TEST

1. List the general characteristics of autism.

2. What is the incidence of autism in the general population?

3. List two problems in obtaining a formal definition of autism.

4. List the current thoughts on the etiology associated with autism.

5. List the criteria put forth in the current Diagnostic and Statistical Manual for diagnosing autism.

6. Check each of the following that refers to a behavior often observed in people with autism:

   - ☐ impulsive and inconsistent
   - ☐ gesture fluently
   - ☐ enjoy diversity
   - ☐ play imaginatively
   - ☐ low initiated communication
   - ☐ enjoy routine

7. List three behaviors often associated with social characteristics of autism.

8. List three behaviors often associated with communication characteristics of autism.

9. List three behavioral characteristics associated with the restricted repertoire of activities and interests characteristic of autism.

10. List three behaviors often associated with learning problems of people with autism.

11. List two characteristic strengths of some people with autism.

12. Approximately what percentage of people with autism also have mental retardation?

13. List three ways a family might cope with having a family member with autism.

14. List at least five disciplines of a balanced interdisciplinary diagnosis assessment team for autism.

15. What skills and behaviors must receive priority and be emphasized in educational programs for students with autism?

16. What does a functional analysis of behavior mean?

17. Can adults with autism live and work in community settings?

18. What do people with autism need to profit from being in integrated settings?

19. Why is early diagnosis and intervention important?

20. How can professionals help families?

REVIEW QUESTIONS 1
Answer Key

1. Check **all** of the following criteria that are used to diagnose autism:

   - ■ Impairment in ability to communicate
   - ■ Impairment in reciprocal social interaction
   - ☐ Bizarre noises and movements
   - ☐ Gross deficit in language development
   - ☐ Self-injury and aggression
   - ■ Disturbance of rate or sequence of development
   - ■ Markedly restricted repertoire of activities and interests

2. List six disciplines that might be used in an interdisciplinary assessment of a person with autism.

   Parents, educator, social worker, speech language clinician, psychologist, doctor, physical therapist, occupational therapist.

3. Which of the following are not true?

   a. Autism is described through observing behaviors.

   b. Autism is a syndrome.

   (c.) Autism is common in males.

   d. Autism is a developmental disability.

   (e.) Individuals outgrow autism.

4. Which one of the following is true?

   a. Autism occurs 4 times more frequently in girls than boys.

   (b.) Prevalence is about 1 in 1,000 in the general population.

   c. Youngest children in the family are most often affected.

   d. Autism rarely occurs with mental retardation.

   e. Autism occurs more in the higher socioeconomic levels.

REVIEW QUESTIONS II
Answer Key

1 Which of the following is the current and most prevalent thought concerning the etiology of autism?

(a.) a combination of genetic and biogenic factors.

b. a combination of emotional problems

c. a combination of environmental factors

2. Who first described autism?

a. Bettelheim

b. DeMeyer

c. Ritvo

(d.) Kanner

e. Tinbergen

3. Check the following phrases that go with the theory of autism being an emotional disturbance:

(a.) Refrigerator mothers

b. Perceptual inconsistency

c. Central cognitive defect

(d.) Wish not to exist

e. Cross-modal association defect

(f.) Separation from mother too early

4. Which of the following are reasons for a lack of understanding about autism?

a. Parents don't care or understand

(b.) Confusion about diagnosis

c. Reluctance of professionals to diagnose emotionally disturbed patients

(d.) The cause of autism in not known

(e.) Uninformed professionals who don't understand the reasons diagnosis often helps the person to receive better programming

(f.) The heterogeneity of the disorder

REVIEW QUESTIONS III
Answer Key

Of the characteristics listed below, mark those often associated with autism.

- ■ 1. Perseveration
- ☐ 2. Love of diversity
- ■ 3. Poor or odd eye contact
- ☐ 4. Imaginative play
- ☐ 5. Answers questions appropriately
- ■ 6. Lacks fear or real danger
- ■ 7. Repetitive movements
- ■ 8. Staring at objects
- ■ 9. Problems with abstract concepts
- ☐ 10. Initiation of communication
- ■ 11. Mental retardation
- ■ 12. Strong attachment to objects
- ■ 13. Explores environment through odd use of senses
- ☐ 14. Generalizes learning to other situations
- ☐ 15. Strives to be independent
- ■ 16. Overselective
- ■ 17. Good long term memory
- ☐ 18. Cerebral Palsy and Down Syndrome

REVIEW QUESTIONS IV
Answer Key

1. Which of the following are typical family emotional reactions to receiving the diagnosis of autism?

   a. isolation
   (b) guilt
   c. loss of hope
   (d) anger
   (e) depression

2. List three ways a family might survive the impact of autism.

   Become informed, work together, utilize outside help

3. Which age groups are entitled to programs by federal law?

   (a) preschoolers

   (b) school age students

   c. adults

   d. aging adults

4. Why should students with autism be taught with other students?

   It is their right, they learn from sociable peers, and they need to learn functional skills like everyone.

5. Is the function of a behavior important to know? Why or why not?

   Yes, so the appropriate skill will be taught that addresses the purpose of the behavior.

6. Can behavior be modified in natural settings? Explain.

   Yes - and should be addressed in the natural setting by teaching appropriate behaviors and skills in context.

7. What skills and behaviors must receive priority and be emphasized?

   The strengths of the individual must be built upon while social interaction and communication must be specifically taught.

8. List six general strategies to remember when teaching someone with autism.

   Use positive approaches, communicate with visual modes, use preferred activities, teach functional skills, teach in context, plan for independence and generalization, provide opportunity for choice making.

SELF TEST
Answer Key

1. List the general characteristics of autism.

   Impairments in social, communicative and sensory skills.

2. What is the incidence of autism in the general population?

   1 in 1000

3. List two problems in obtaining a formal definition of autism.

   Uninformed professionals and heterogeneity of the disorder.

4. List the current thoughts on the etiology associated with autism.

   Probably a combination of genetic and biogenic factors.

5. List the criteria put forth in the current Diagnostic and Statistical Manual for diagnosing autism.

   Onset in infancy or early childhood, qualitative impairment in reciprocal social interactions and in communication with a markedly restricted repertoire of activities and interests.

6. Check each of the following that refers to a behavior often observed in people with autism:

   - [x] impulsive and inconsistent
   - [ ] gesture fluently
   - [ ] enjoy diversity
   - [ ] play imaginatively
   - [x] low initiated communication
   - [x] enjoy routine

7. List three behaviors often associated with social characteristics of autism.

   Relate to people with difficulty, lack understanding of social cues, lack empathy.

8. List three behaviors often associated with communication characteristics of autism.

   Slow in using and understanding gestures, difficulty understanding abstract concepts, initiate communication infrequently and/or inappropriately.

9. List three behavioral characteristics associated with the restricted repertoire of activities and interests characteristic of autism.

Resist change in routine or environment, may stare or fixate on lights or moving objects, may explore the environment through inappropriate licking or handling, may perseverate on activities.

10. List three behaviors often associated with learning problems of people with autism.

Develop unevenly within and across skill areas, resist change, difficulty with unstructured time and waiting, problems shifting attention.

11. List two characteristic strengths of some people with autism.

Good long term memory, enjoy routines, stamina.

12. Approximately what percentage of people with autism also have mental retardation?

70 - 80%

13. List three ways a family might cope with having a family member with autism.

Become informed, work together, seek and utilize outside help.

14. List at least five disciplines of a balanced interdisciplinary diagnosis assessment team for autism.

Education, psychology, speech and language, medical, social work, occupational therapy.

15. What skills and behaviors must receive priority and be emphasized in educational programs for students with autism?

Strengths of individual, social interaction ,and communication.

16. What does a functional analysis of behavior mean?

It means keeping data to analyze the purpose(s) of behavior so you can determine new skills to replace the behavior.

17. Can adults with autism live and work in community settings?

Yes, with support

18. What do people with autism need to profit from being in integrated settings?

Appropriate individualized program plans and supportive , informed adults and peers.

19. Why is early diagnosis and intervention important?

To begin appropriate programming early and view the problems as part of the disability rather than as an emotional or behavior disorder.

20. How can professionals help families?

By listening to them, including them, and supporting them. Establish a collaborative effort toward helping the individual.

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SCENARIO

Read the following scenario and complete the corresponding questions on the evaluation.

Scenario:

Randy, age 21, is the oldest of three boys, both brothers being non-handicapped. He was born with the routine use of forceps and no notable prenatal complications, after an unremarkable pregnancy. There appears to be no family history of neural disorder. He began having some difficulties in eating and sleeping and was noted to be hyperactive by six months. When he produced no speech by age two, his parents sought medical advice.

Randy was referred to a clinic of doctors at a local hospital where he was diagnosed as having autism by the end of his third year. He participated in a research project on intervention strategies for the following two years.

He was briefly self-injurious at ages three and four, and began throwing tantrums at five. He attended special education classes at three different schools in five years. He rarely spoke, but learned some sign.

In August of his tenth year, Randy entered a special research institute. There at age ten he made his first sounds and was beginning to shape these sounds into rudimentary one-word vocalizations. He had his first grand mal seizure at age nine and his second at age ten. He first became aggressive in his eleventh year and at times his aggression has been severe.

Currently, Randy uses a total communication system which consists of manual sign language, oral speech, and a picture communication board. Randy speaks in short sentences, but his speech is basically unintelligible. Randy has learned approximately 50 manual signs. He uses about 25 functionally. He has average dexterity and has shown recent advances in his fine motor skills. In a recent assessment he was able to assemble a small tool consisting of three parts ten times without error. Randy can match and sort well. He swims laps, can ride a bike, jog, and likes to go out to eat.

EVALUATION FORM FOR MODULE:
INTRODUCTION TO AUTISM

1. Do you think Randy will be able to work in a competitive work environment? Mark the number which closely resembles your current thoughts.

VERY LIKELY NEUTRAL VERY DOUBTFUL

1..... 2..... 3..... 4..... 5

2. Would you like Randy to move to your neighborhood in a group home? Mark the number which closely resembles your current feelings

STRONGLY PREFER NOT NEUTRAL FINE WITH ME

1..... 2..... 3..... 4..... 5

3. Randy's group home is applying for a YMCA membership. You are on the YMCA board. Mark the number which represents you current position.

ADVOCATE AGAINST NEUTRAL ADVOCATE FOR

1..... 2..... 3..... 4..... 5

4. What was most informative to you in this module?

5. Will anything you learned be useful in your job?

6. What are your suggestions for changes or improvements in the module?

7. What other information on autism would be helpful to have in self-instructional form?

Your Job Title:_____ Your major (if student):_____

Date Completed:_____

Indiana Resource Center for Autism

PUBLICATIONS AND VIDEOTAPES
AVAILABLE MATERIALS – JULY 1993

Autism Assessment Sourcebook. (1992-93). 122 p. $7.00. A composite book of short papers on the diagnosis and assessment of individuals with autism including sample reports.

Autism Training Sourcebook. (1993-94). $10.00. Including: Assessment, Autism, Behavior Management, Communication, Functional Programming, Medical, Self Help, Social Leisure, Bibliographies (Autism: Behavioral Issues, Autism: Vocational Programming, Functional Communication, Medical Aspects of Autism, Selected List of books on Autism, Sexual Aspects of Autism).

Bibliographies of Topics in Autism. (1992). 208 p. $8.00. Edited by Suzie Rimstidt. Ninety-five selected bibliographies on specific topics in autism have been collected by the interdisciplinary staff of the Resource Center from the large collection of current articles, papers, book chapters, videos, and other printed materials. The bibliographies include educational, psychological, and medical topics such as facilitated communication, functional programming, beta blockers/medications and behavior, e.g., motivation/reinforcement.

Community Assessments in the Personal Management Domain. (1987). $5.00. A sample of individual, site-specific assessments to provide information about the skills that need to receive priority in the individual plan. Seventeen assessments are included in the personal management domain. Communication and social skills are built into each one.

Competencies for People Teaching Individuals with Autism. Dalrymple, N. (1993). 29 p. $2.00. This booklet has been updated twice since the original in 1983. Three levels of competencies are described from level 1 which requires the trainee to identify, discuss, or define; to level 2 which requires participating, using, and evaluating; to level 3 which requires demonstrating, teaching, and training others. These competencies provide a base from which to build training activities that result in well-trained individuals who know how to teach, support, and advocate for people with autism across the age span.

Facts About Autism. (1990, Spanish edition 1992). 17 p. $1.00. By Marci Wheeler, Suzie Rimstidt, Susan Gray, and Valerie DePalma. For anyone interested in autism awareness. Provides short concise information describing autism, diagnosis, needs of the person with autism from diagnosis through adulthood. Information on the Autism Society of America (ASA) chapters in Indiana is included along with a description of the Indiana Resource Center for Autism and a suggestion of books to look for in the local library.

Functional Programming for People with Autism: A Series....

Enhancing Communication in Individuals with Autism Through the Use of Pictures and Word Symbols. 17 p. $1.50. By Michelle Winner. (1989). Impaired expressive communication is a barrier for persons with autism. This paper discusses the philosophy, description and implementation of visually aided communication including communication boards and computers; eye gaze; manual signs; and gestures.

7647 **Developing a Functional and Longitudinal Individual Plan.** By Nancy Dalrymple. (1989). 11 p. $1.50. Emphasizing strengths rather than weaknesses, the provider must plan activities for even preschoolers with functional adult goals taking priority. This booklet suggests possible goals and specific short term activities in self-care, personal management, home care, social and leisure, and work.

7646 **Functional School Activities I.** by Nancy Dalrymple. (1980). Revised by Barbara Porco. (1989). 15 p. $1.50. This booklet is designed to help the teacher with specific "school" or "pre- academic" skills. Techniques to increase sitting and attending as well as matching and fine motor skills are explained and illustrated.

7645 **Growing Towards Independence By Learning Functional Skills and Behaviors.** By Barbara Porco. (1989). 5 p. $1.50. This booklet explains the philosophy of the IRCA which states that priorities of what and how to teach skills to persons with autism should be established on the basis of functionality.

7644 **Learning Self-care Skills**. By Valerie DePalma and Marci Wheeler. (1991). 30 p. $1.50. This booklet is designed to help parents and instructors develop and implement programs for self-care skills such as eating and grooming. Examples of practical strategies and steps to consider when working with a learner with autism are outlined throughout the booklet.

7643 **Reading.** By Nancy Dalrymple. (1980). Revised by Barbara Porco (1989). 29 p. $1.50. When teaching reading, it is important to make the material relevant and within the individual's experience. This booklet includes sections on How to Begin, Building Comprehension and Developing a Lesson.

7642 **Learning to be Independent and Responsible.** By Nancy Dalrymple. (1989). 11 p. $1.50. People with autism build trust in people and environments through successful interactions. Individualized, supportive programs utilizing positive instructional and environmental supports that lead to increased opportunities, choice and motivation are described in this booklet.

7649 **Sex Education: Issues for the Person with Autism.** By Nancy Dalrymple, Susan Gray and Lisa Ruble. (1991). 18 p. $1.50. Discusses issues of sexuality and provides some methods for instruction with person with autism.

7641 **Toileting.** By Nancy Dalrymple and Margaret Boarman. (1989) (Revised in 1991). 17 p. $1.50. Self-care in toileting is one of the areas that persons with autism frequently have difficulty managing and are often confused by training. This booklet discusses issues and strategies of teaching independent, socially acceptable toileting skills.

7653 **Helpful Responses to Some of the Behaviors of Individuals with Autism.** By Nancy J. Dalrymple (1992). 36 p. $2.00. This booklet discusses comments that are often made about individuals with autism by people who do not understand the disorder. After each comment, an explanation is provided based on the understanding of autism; then some possible helpful responses for each comment are listed. The intent of the booklet is to help a wide audience be able to respond to individuals with autism in more supportive ways.

7640 **Helping People with Autism Manage Their Behavior.** By Nancy J. Dalrymple. (Revised 1993, Spanish edition 1992). 39 p. $5.00. Covers the broad topic of helping people with autism manage their behavior by analyzing the learning environment and the purpose of the behavior and then designing positive programs to change behavior.

Identifying High Functioning Children with Autism. By Stine Levy. (1986). 11 p. $1.00. Compares and contrasts high functioning children with autism with those who have learning disabilities and emotional disturbances.

Indiana Autism Needs Assessment Highlights. (1990). No charge. Highlights of data obtained by the Indiana Resource Center for Autism as mandated by the Indiana Legislative Commission on Autism. Summarizes parent and service provider surveys on needs of persons with autism.

Indiana Autism Needs Assessment Survey. (1990) $3.00. Results of the 1990 parent and service provider needs assessment. The 1990 survey continues a Public Law 210 mandate for the Indiana Resource Center for Autism to conduct a statewide needs assessment every three years (also done in 1984 and 1987) to determine the status of services provided in Indiana to persons with autism and their families.

Indiana Resource Center for Autism Final Report. (1992-93). $2.00. Data on information dissemination, research, and training activities at the Indiana Resource Center for Autism during the 1991-1992 fiscal year.

Indiana Resource Center for Autism-Information Packet. (1993-94). $1.00. Describes the history and activities of the Indiana Resource Center for Autism. Outlines information dissemination, outreach training, and interdisciplinary student training objectives. Reports on activities during past year. Includes a list of training papers, information sheets, and a selected list of books.

Instructional Modules on Autism. By Nancy Dalrymple, Barbara Porco, and Jaesam Chung. (1993). $95.00. These teaching modules which present current information on autism were originally developed for university and college social service courses. Now available to anyone teaching about autism, Module 1 focuses on the nature of autism and Module 2 on how best to interact with persons with autism in family, school, community and work setting.

The set includes an instructional manual; two books, Introduction to Autism and Bibliographies of Topics in Autism; overhead transparencies; two videotapes Being Friends and Three Case Studies, the booklet Helpful Responses to Some of the Behaviors of Individuals with Autism and training papers on topics in autism.

7638 **Introduction to Autism: A Self Instructional Module.** (Revised 1992, Spanish edition 1992). 50 p. $5.00. This module is designed to provide an introduction to autism to service providers, students, and parents, and to help answer the question, "What is Autism?" (See also the videotape, *Introduction to Autism*).

7639 **Learning Together.** By Nancy Dalrymple. (1979, Spanish and Korean editions 1992). 27 p. $2.00. Introduces preschool and early elementary school children to a classmate who has autism.

7637 **Let Community Employment be the Goal for Individuals with Autism.** By Joanne Suomi, Lisa Ruble and Nancy Dalrymple. (1992). 61 p. $5.00. A guide designed for people who are responsible for preparing individuals with autism to enter the world of work.

Psychological Evaluation of Children with Multiple Handicaps: A guide for Parents. By Stine Levy. (1987). 15 p. $1.00. Describes what happens during a psychological evaluation of children with severe and/or multiple handicaps.

Record Book for Individuals with Autism. (1990). 29 p. $4.00. By Nancy Dalrymple and Beverly Purdue. This book was developed with parent input to provide one place to keep information about a child so that it is organized, easily accessible and can be copied as needed.

Social Series:

7651 **Some interpersonal social skill objectives and teaching strategies for people with autism,** by Nancy J. Dalrymple (1992), 31 p. $2.00

7650 **Some social communication skill objectives and teaching strategies for people with autism,** by Nancy J. Dalrymple (1992), 32 p. $2.00

These booklets are an update of chapters from the original sourcebook, Teaching Social and Leisure Skills to Youth with Autism (1981). The need and general strategies for teaching social interaction skills and social communication skills are discussed briefly, then a sample of objectives with a rationale, lead-up and modification ideas, teaching procedures, motivation, precautions, and related objectives for each objective are presented.

Teaching Community Skills and Behaviors to Students with Autism or Related Problems of Communication and Social Interaction. (Revised 1988). 117 p. $7.00. Developed by Kim Andis, Judy Brookhiser, Nancy J. Dalrymple, Dana Flanders, Joy Lucas, & Jill McLaughlin. This sourcebook covers the circular process in successful community-based teaching emphasizing the needs of the person with autism and the philosophy of community integration. Practical methods of consideration in assessing student and family interest and needs, assessing community resources to meet the needs, and assessing students in community sites are included.

VIDEOTAPES FOR INFORMATION AND TRAINING

Autism: Being Friends. (1991). VHS. 8:08 minutes. $10.00. Produced by the Indiana Resource Center for Autism and WTIU, Indiana University Public Television Bloomington, IN.
Summary: This autism awareness videotape was produced specifically for use with young children. The program portrays the abilities of the child with autism and describes ways in which peers can help the child to be a part of the everyday world.

Autism: Learning to Live. (1990). VHS. 58:46 minutes. $30.00. Produced by the Indiana Resource Center for Autism and WTIU, Indiana University Public Television, Bloomington, IN.
Summary: Filmed throughout the state of Indiana, this public television documentary focuses on children and young adults with autism as they learn in community settings. Sites vary from a family home, to a bakery, to a classroom. Teachers, friends, a principal, a speech clinician, a job coach, and parents talk about the ways they have helped specific individuals with autism learn and about what they have learned from these individuals. Recommended: For use by parents, professionals and the general public. This videotape is designed specifically for use as an autism awareness tape and is the first in a series of three.

Autism: Stubborn Love. (1991). VHS. 28:54 minutes. $25.00. Indiana Resource Center for Autism and WTIU, Indiana University Public Television, Bloomington, Indiana.
Summary: This videotape dispels myths that blame parents for their children's autism. It is the story of Vivian Koby's struggles and successes as she advocated for and lived with her son, Paul. Now that Paul is an adult there are more services for people with autism; however, it is still parents who must interpret their child and his or her needs to the world.

The following videotapes were produced for use in training/awareness activities and are not intended for broadcast; they are onsite, non-broadcast quality.

Building Independence Through the Use of Adaptations and Enablers. By Sheila Wagner. (1989). VHS. 20 minutes. $25.00. A training videotape designed for the use of group homes, adult day services, agencies, schools, and parents. It shows the teaching of independent skills and behaviors to individuals with autism and other developmental disabilities.

Creative Programming for Children with Autism Part I: Headstart/Kindergarten and Part II: First Grade. by Barbara Porco. (1988). VHS. 44 minutes. $25.00. Children with developmental disabilities are increasingly being integrated into classrooms with their peers. These videotapes show a high functioning child with autism who is integrated into school programs based on a creative programming approach by the school/parent team. The tapes focus on the planning issues, implementation practices and critical factors which contribute to successful integration.

Health Care Desensitization. By Susan Gray. (1989). VHS. 19 minutes. $25.00. A training videotape for teachers, parents, health professionals, and group home staff showing how the desensitization procedure to medical, dental, and optometric exams was applied to preschool and adolescent students with autism and their successful cooperation with the subsequent health care.

Introduction to Autism. (1991). VHS. 30 minutes. $25.00. By Bill Scroggie and Chris Lewis. This tape covers key points from the Introduction to Autism: Self Instructional Module. It contains portions of the Autism series, but narrates specifically to provide a clear, accurate introduction to understanding the disability.

Managing Behaviors in Community Settings. By Nancy Dalrymple. (1988). VHS. 28 minutes. $25.00. A training videotape for teachers, parents, paraprofessionals, group home, and recreational staff. This tape takes the viewer through the development of a philosophy, searching for the purpose of behaviors, environmental plans, and reactive plans. Students with autism are the stars as they are involved in community life, from the trips to the dentists, work at Holiday Inn, to the ski slopes and lakes.

School Inclusion of a High Functioning Student with Autism. A high functioning child with autism at ages 4 and 11. (1993). VHS. 32 minutes. $25.00. By Barbara Bailey Porco. This videotape was designed for parents, school staff and others interested in learning about characteristics of high functioning autism over time (preschool through elementary school) and the strategies and supports which facilitate school inclusion.

Teaching Nontraditional Communicative Behavior. By Annamaria Mecca and Beverly Vicker. (1989). VHS. 19 minutes. $25.00. This videotape focuses on an often overlooked type of augmentative communication, i.e. gestural communication. The tape discusses several assessment and intervention strategies which can be used with individuals with autism who do not effectively use oral speech as their primary means of communication. On the tape three students of varying ages and cognitive abilities are shown to help illustrate the strategies.

We like Eating Out Too: The Use of Aided Communication in the Community. (1990). VHS. 11 minutes. **For loan only**. By Beverly Vicker. Edited by Glenn Simonelli.
Summary: This public awareness video presents general information about the need for augmentative communication for many individuals with various disabilities. The use of aided communication, i.e., the use of some physical material to facilitate communication, is demonstrated through footage of a 17 year

old individual with autism who has severe cognitive impairment. A manual provides additional aids for conducting public awareness activities.
Recommended: For use by individuals who have some knowledge about augmentative communication and who can answer follow-up questions from the audience. The awareness level tape can be used with a variety of audiences including the general public, college students, upper elementary school age individuals and above, and for professionals/paraprofessionals who are unfamiliar with augmentative communication.

PUBLISHED ARTICLES (Outside Journals & Books)

Dalrymple, N. & Angrist, M. (1988, July). **Toilet training a sixteen- year-old with autism in a natural setting.** British Journal of Mental Subnormality. 117-130. Describes a program used to teach toileting behaviors and skills to a 16-year-old girl with autism and severe mental retardation while she was placed in a community-based residential and vocational program.

Dalrymple, N. & Angrist, M. (1989). **Autism resources at the higher education level in Indiana.** "Letter to the Editor" Journal of Autism and Developmental Disorders, 19(1), 173-174. Results of a survey of autism awareness among higher education professionals in Indiana. Covers teaching about autism at the undergraduate and graduate levels and availability of relevant materials in campus libraries.

Dalrymple, N. & Ruble, L. (1992, June). **Toilet training and behaviors of people with autism: Parent views.** Journal of Autism and Developmental Disorders, 22(2), 265-275.

Henning, J. & Dalrymple, N. (1986). **A Guide for developing social and leisure programs for students with autism.** In E. Schopler and G. Mesibov (Eds.), Social behavior in autism. New York: Plenum Press. Discusses specific strategies for teaching self-care and functional academic skills, interpersonal skills, social communication skills, leisure skills, and community skills.

Levy, S., Zoltak, B. & Saelens, T. (1988). **A Comparison of obstetrical records of autistic and non-autistic referrals for psychoeducational evaluations.** Journal of Autism and developmental Disorders, 18(4), 573-581.

Ruble, L. & Dalrymple, N. (1993). **Social/Sexual awareness of persons with autism: A parental perspective.** Archives of Sexual Behavior. 22(3), 229-240.

Schmidt, G., McLaughlin, J., & Dalrymple, N. (1986, September). **Teaching students with autism: A sport skill specialist's approach.** Journal of Physical Education, Recreation, and Dance, 60-63. Describes step-by-step procedures to teach a person with autism independent skills in such sports as swimming and snow skiing.

Vicker, B. (1987). **Communication > talking; Part I: Nonverbal communication that may be overlooked or misinterpreted.** Communicating Together, 5(3), 9-11. Discusses the importance and interpretation of nonverbal communication.

Vicker, B. 1987. **Communication > talking; Part II: A rationale for the use of augmentative communication.** Communicating Together, 5(4) 8-9,2. Defines augmentative communication and discusses its advantages for handicapped individuals. Explains the differences between aided and unaided augmentative communication.

Vicker, B. & Monahan, M. (1988). **The diagnosis of autism by state agencies.** Journal of Autism and Developmental Disorders, 18(2), 231-240. Surveys the Departments of Mental Health and Departments of Education in all 50 states regarding their diagnostic criteria for autism.

Zoltak, B. (1986). **Autism: Recognition and management.** Pediatric Nursing, 12, 90-94. Describes the etiology, identification, and treatment of autism.

Indiana University
Institute for the Study of Developmental Disabilities
The University Affiliated Program of Indiana
Indiana Resource Center for Autism
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INDIANA UNIVERSITY

INSTITUTE FOR THE STUDY OF DEVELOPMENTAL DISABILITIES

Indiana Resource Center For Autism
Order Form

Publications	Price	Quantity
Autism Assessment Sourcebook	$ 7.00	_____
Autism Training Sourcebook	$10.00	_____
Bibliographies of Topics in Autism	$ 8.00	_____
Community Assessments in the Personal Management Domain	$ 5.00	_____
Competencies for People Teaching Individuals with Autism	$ 2.00	_____
Facts About Autism	$ 1.00	_____
Spanish edition	$ 1.00	_____
Functional Programming for People with Autism: A Series...		
• Developing a Functional and Longitudinal Individual Plan	$ 1.50	_____
• Enhancing Communication in Individuals with Autism Through the Use of Pictures and Word Symbols	$ 1.50	_____
• Functional School Activities I	$ 1.50	_____
• Growing Towards Independence By Learning Functional Skills and Behaviors	$ 1.50	_____
• Learning to be Independent and Responsible	$ 1.50	_____
• Learning Self-care Skills	$ 1.50	_____
• Reading	$ 1.50	_____
• Sex Education: Issues for the Person with Autism	$ 1.50	_____
• Toileting	$ 1.50	_____
Helpful Responses to Some of the Behaviors of Individuals with Autism	$ 2.00	_____
Helping People with Autism Manage Their Behavior	$ 5.00	_____
Spanish edition	$ 5.00	_____
Identifying High Functioning Children with Autism	$ 1.00	_____
Indiana Autism Needs Assessment Highlights	No Charge	
Indiana Autism Needs Assessment Survey	$ 3.00	_____
Indiana Resource Center for Autism Final Report (1992)	$ 2.00	
Indiana Resource Center for Autism Information Packet	$ 1.00	
Instructional Modules on Autism	$95.00	_____
Introduction to Autism: A Self Instructional Module	$ 5.00	_____
Spanish edition	$ 5.00	_____
Learning Together	$ 2.00	_____
Spanish edition	$ 2.00	_____
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